

PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

Utah -- Family-Directed Support Network for Families of People with Disabilities

Issue: Support, information, and resources for family caregivers

Summary

Utah's Family Council is an opportunity for families of individuals with disabilities to provide support, education, and resource information to one another. The Family Council is a statewide, family-directed support network available to all families of individuals with disabilities, including families who do not receive publicly funded services. A formal evaluation of the Council's effectiveness has not been conducted, but state and Council staff report Council participants benefit from the increased support, awareness, and empowerment.

Introduction

Families of people with disabilities in Utah often did not know how to seek publicly and privately funded services. Most

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supports available to families were parent training centers and support groups that catered to individuals

with particular disabilities. Several families in Utah formed the Family Council, a nonprofit organization that enables all families of people with disabilities to support one another, share ideas, and learn about available services. Using funds from a Self-Determination Grant from the Robert Wood Johnson Foundation, the State of Utah provided support to increase availability and awareness of the Family Council's services throughout the state.

This report briefly describes the activities and resources available through the Family Council, the Council's structure, and how the Council expanded with the assistance of Utah's Division of Services for People with Disabilities (DSPD). The Family Council web site, Utah's DSPD, and a Family Council representative provided information necessary to complete this report.

Background

Utah increased the Family Council's availability after a January, 2000 report written by families

detailed what worked and did not work in Utah's family support services. Prior to the report, The Family Councils existed within a few communities. The previous Family Councils received informal support from the DSPD, such as meeting space and secretarial support, but they received no financial support from DSPD.

Intervention

The Family Council in Utah has a total of 35 local, regional, and state level Family Councils. The Regional Councils represent the four regions of the state and consist of selected Local Council officers. The State Council consists of representatives

from the four Regional Councils. The Chair and the Vice Chair of the State Council meet with the Director of

Family Council members help one another identify services and provide other types of assistance.

the DSPD on a monthly basis to provide feedback regarding issues and policies from a family members' perspective. At each level, family members of individuals with disabilities completely manage the Councils.

Families learn about the Family Council in many ways including the DSPD and Family Council web sites, Family Council newsletters, providers, conferences, schools, brochures, and word of mouth. DSPD also sends letters to families informing them of the Family Council. Originally,

the Family Council served families of children with disabilities. The Family Council currently welcomes all families of people with disabilities, regardless of age or diagnosis.

Family Council members often help one another identify available services and funds, decipher technical language, complete paperwork, locate employment and equipment, and identify other tools necessary to advocate for their family members. The Family Councils also provide input and suggestions to DSPD and the state legislature regarding services and policies that affect people with disabilities.

Local Councils also initiate projects to improve the quality of life of people with disabilities. Projects vary according to the needs of the local community. Examples of projects include creating a public awareness campaign for elementary schools, providing baby blankets with support information to mothers of newborn babies with disabilities, developing recreational programs, mentoring new parents, and assessing the quality of provider services.

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Implementation

Funds from a Self-Determination Grant from the Robert Wood Johnson Foundation assisted the Family Council to establish new Local Councils and increase local awareness of the network of Family Councils available. The initiative took approximately one year. Due to the high demand for the Family Councils, many Local Councils were implemented by families between January and April of 2000.

The first step to creating a new Local Council is an informational dinner. The Family Council plans a dinner in a community when one or more families request to establish a Local Council. When planning the informational dinner, the State Chair invites families of people with disabilities identified by the Family Council and by DSPD. These meetings are usually very successful in raising interest for a Local Council,

and officers are often elected by the end of the meeting.

For new Councils, the Family Council provides training and materials to guide new officers on how to implement and manage a Council. Topics covered in the training and materials provided include how to run elections, how to create budgets, and how to work with difficult people. State Family Council officers identified these topics for training through previous Family Council experience and through general knowledge of managing organizations.

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When a Local Council is established, the Council's first project is to identify the needs of the community. The Local Council also must provide advocacy and assistance to people with disabilities and participate in the Regional Council meetings. Local Councils must also provide orientation for new recipients of DSPD services.

The cost to implement and manage each of the Councils depends on the number of participants and the population represented within the Council. Costs incurred include transportation, guest speakers, refreshments and space for meetings, telephone calls, printing, marketing, and training.

All members of the Family Council volunteer their work and time, except for the Chair of the State Family Council. DSPD offers supplemental respite care for attending meetings to State, Regional, and Local Council officers who receive publicly funded services through DSPD. DSPD offers reimbursement for travel and respite costs to officers not receiving publicly funded services.

DSPD provides one case manager (known as support staff) to each Local Council to provide support services. These services include sending out mailings, photocopying, providing transportation, and making telephone calls. DSPD decreases other job responsibilities for the support staff in return for their assistance with the

Council, which typically requires an investment of ten to fifteen hours per month. Ensuring that support staff remain in their supportive roles and not attempt to lead the Local Councils can be challenging at times.

One challenge in establishing Family Councils is communication and travel difficulties in rural areas. Local Councils represent the entire state, and rural Councils cover large geographic areas. Council members use the Internet and email to improve communication and move projects forward with fewer in-person meetings.

Impact

180 parents are in official leadership roles within the Utah Family Councils. Throughout the Local, Regional, and State Councils, there are approximately 140 additional Council members that participate in various Council projects. Typical attendance for Local Council meetings varies between 8 and 30 family members. Attendance of Regional Council meetings ranges from 25 to 40 family members.

No formal analysis of the Council's effectiveness has been performed. Quarterly reports

document the Councils' accomplishments, including Local Council projects. Informal indicators of the Council's effectiveness are unsolicited statements of satisfaction and the strong communication network that has been established among families. The communication network is evident through Council publications, the website, attendance at Council meetings and Council conferences, and parent-to-parent networking.

DSDP provides up to \$60,000 annually for support of the Family Council. This funding provides compensation for the State Chair, secretarial support and accounting services for the State Council, office and printing supplies, small operating budgets for each of 35 Local and Regional Councils, and travel reimbursement or respite care for Council Officers.

Contact Information

For more information about Utah's Family Council, please contact Pheobe Blackham, State Chair of the Family Council at 1-877-352-2221 or at Pmbalp@aol.com. Online information about Utah's Family Council is available at www.statefamilycouncil.org.

Some Discussion Questions:

In addition to the state, what other organizations may provide support for the Family Council?

How can the Family Council's effectiveness be measured?

Erin Barrett, L.S.W., wrote this report, one of a series of reports by The MEDSTAT Group for the U.S. Centers for Medicare & Medicaid Services (CMS) highlighting promising practices in home and community-based services. The entire series will be available online at CMS' web site, <http://www.cms.gov>. This report is intended to share information about different approaches to offering home and community-based services. This report is not an endorsement of any practice.